

# Hannah Soyer

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## SUMMARY KEYWORDS

disabled, pandemic, hannah, friends, people, lives, safety precautions, disability, sacrificing, helpers, experience, closer, parents, true, remember, care, high risk, home, affect, championing

## SPEAKERS

Bushra Nayeem, Hannah Soyer

### **Bushra Nayeem** 00:00

Hello everyone, this is today is 16th of January 2021. I'm Bushra Nayeem. I'm a historian and an educator. Today I'm going to have a conversation with Hannah Soyer, who is currently living in Iowa. We are going to record this conversation for COVID Disability Archive. We hope this archive will help us to know the experience and struggle of disabled, sick and chronically ill people during this pandemic. So, Hannah, how are you doing today?

### **Hannah Soyer** 00:29

I'm good. Thank you. That was such a lovely introduction.

### **Bushra Nayeem** 00:34

So can you tell us more about you, your identity and about yourself?

### **Hannah Soyer** 00:41

Yeah, so my name is Hannah Soyer. I'm 26. My pronouns are she/ her. And as you said, I'm currently living in Iowa. I'm a white queer disabled woman.

### **Bushra Nayeem** 00:55

Okay, Hannah. So when did you first learn about the pandemic? And what was your experience with this?

### **Hannah Soyer** 01:04

Um, so actually, I and I know I wrote this answer, and then I was thinking about it. And it was actually before this. I had a friend who was telling me that she was talking with her brother and her brother hadn't heard of the Coronavirus. And she was really appalled by that. And I was like, Well, I don't know what the Coronavirus is, I've never I don't know what this is. And that was probably, you know, the very beginning of March, maybe late February of 2020. And then I remember one of my students because I'm a graduate teaching assistant at the University of Kansas. And I remember one of my students, and he was from a town close to Wuhan, China. And so he, and he was writing about this in a project as

well. And, you know, really talking about how serious this whole thing was. I remember the day before leaving for spring break in March. He asked me where he could buy disposable face masks. And I had no idea. And at this point, it felt like the seriousness of the Coronavirus hadn't really hit the US, at least from my perspective. So then I went home to Iowa. And that was, I was in Kansas, I went home to Iowa for spring break. And I remember things getting serious, real fast. I had a helper, who's also one of my really good friends, come up from Kansas, to Iowa for half of spring break. And when she got to my house, where I've been staying with my parents, she made a comment about how the Coronavirus wasn't serious. And I was already scared of it and scared of what was going to happen because of how high risk I am. And I think within a matter of like two days, her perspective, you know, completely changed, as I think a lot of people in the country like things suddenly got way more serious way more quickly. I also have this distinct memory. That same week, my friend was still here. I have a very distinct memory of crying in my room, because of how overwhelmed and upset I was. And I, from my perspective, even early on at that point, I felt like people were not taking this as seriously as they should be. Yeah,

**Bushra Nayeem 03:42**

Yeah, it's true. I mean, most of the people didn't take it very seriously in the beginning. It's true. So yeah. So Hannah, I would like to know, what has your experience been as a disabled person throughout this pandemic?

**Hannah Soyer 04:01**

Yeah, so I have spinal muscular atrophy, which is a neuromuscular disease. It's a form of muscular dystrophy. It doesn't affect my immune system. So I'm not technically immunocompromised, but it does affect my respiratory system. So my lungs are very weak. And so I'm already at high risk for pneumonia. And because COVID-19 affects your lungs, it's not something I can risk catching. I used to live in Lawrence with my personal care attendants, because that's where I'm going to grad school and where I'm working right now. But I was unable to find enough helpers who were able and willing to quarantine to a level that I was comfortable with. So I decided to move back home with my parents. And I really think you know, it's it is this weird I don't know, like some people, some of my helpers definitely are not able to quarantine you know, and that's that I think is the thing. There are so many people in this country who are not able to stay home and not able to, you know, not be around their roommates or what have you. So there are definitely, I think systemic ways that systemic barriers to, you know, taking the steps that need to be taken to eradicate the virus. But yeah, so I moved back home with my parents, and I'm very lucky that both of them are able to help me. And both of them are also primarily able to work from home. I have friends, I have a friend with SMA, who lives in Canada, and she, her parents aren't well one, they are not able to provide the care that she needs, just because they're getting older. And then her dad also works at a nursing home. So that was really not an option for her to go home. You know, so I mean, I have a lot of privilege in the fact that I was able to come home and the fact that I'm able to exercise the safety precautions that I'm able to. At one point, I realized that high risk disabled people who rely on personal care assistance, I think, really, throughout this pandemic, I think we've been put in this impossible position. Because we literally need other people to survive. We rely on our personal care assistants to help us and to get us out of bed in the morning. Um, you know, like, literally keep us alive, and yet at the same, at the same, or on the same. I'm blanking on the word. On the other hand, you know, we are risking our lives if our helpers are not able

or willing to follow the safety precautions we need. So it seems like this sort of catch 22 Um, let's see, what else did I want to say? So, yeah, I mean, you know, if I think about how has my experience been as a disabled person throughout this, I would say that it's been incredibly isolating, and incredibly difficult. I'm sacrificing a lot of freedom and independence, so I can stay safe. While so many others are refusing to sacrifice small things, like going to gatherings, parties, going out to eat, or to bars, simply because they don't want to. And I think a really difficult thing with that is that, we know that those activities spread the virus. And we also know that the virus is disproportionately killing people with pre existing conditions. And there was a CDC report from I think, this summer, maybe it was this fall that found that 98% of COVID deaths are people with pre existing conditions. So I mean, to me, like, the connection there is very clear. And it's hard to not take those sorts of activities, as you know, a literal disregard for my life and for my community.

**Hannah Soyer 08:54**

And we also know that COVID deaths are disproportionately affecting people of color. And so again, like it's hard to not see those specific activities as being very selfish and privileged. I have never experienced this level of disregard for the lives of disabled and chronically ill people before. Which to some extent, I think, is a privileged thing to say because a lot of a lot of disabled people of color have been experiencing, you know, various levels of oppression, I think, historically, much more than say, like, I have been, and so I think that there are probably many disabled people who have in fact, you know, experienced this level of disregard before. And it's sort of like I knew that it existed in our society and culture. But I've never felt it this blatantly before. That was a really long answer.

10:07

Yeah, yeah, it's true, Hannah, but I'm really glad that you had the opportunity to stay with your parents.

**Hannah Soyer 10:13**

Me too. I'm very, very grateful. Yeah. And

**Bushra Nayeem 10:17**

Also, it's true that it is very depressing to see that people who have the opportunity to stay at home, but they are not. They are not taking the safety measures and not following the rules properly and creating risks for the people who don't have these opportunities. So Hannah, I would like to know, what have your relationships with people been like throughout this? I mean, during this pandemic, have you have your relationships with other people changed?

**Hannah Soyer 10:47**

Yes, so they have. I think in in many instances, I have gotten closer to people throughout all of this. One specific instance of that is, I have made friends with and then gotten closer to friends in the disability community, who are struggling with the same things that I'm struggling with. I think that that has been, that has been something that has been very, I don't know, like a weird silver lining to all of this, just to see, so many disabled people come together, and, you know, talk about this and share resources has been really nourishing. And I also, I also have had friends, able bodied friends, who I also have gotten closer to throughout all of this, because we've been able to have really deep conversations about, you know, why this is hurting, and why this is so painful to see and why this is so

hard. But I have also struggled with a lot of friendships, because in many instances, I haven't felt supported or heard. And so it has sort of been I mean, you know, it's almost been a year now, since this all started. And so it's sort of been this long. Excuse me, ongoing balance for me of maintaining connections, and maintaining friendships, for my own survival and mental health. And then also having to balance that with, you know, shielding myself from relationships that are draining. Yeah,

**Bushra Nayeem 12:41**

It's true. So I mean, if you have had to distance yourself from people, because you haven't felt comfortable with the lack of safety precaution, how has this gone?

**Hannah Soyer 12:54**

Um, I would say that... I would say that I've mainly like had to distance myself from people, internally, you know, like, like, inside, I've had to be like, Okay, I cannot put this amount of energy into this relationship right now. Because I don't feel supported, which is something that I need from friendships. And so I mean, I guess what I should say is, there has never been, there's never been an instance of me, you know, explicitly saying to one of my friends, hey, I need to distance myself from you. It's more just being small moments of myself, saying, Okay, I need to take a step back. And I also think that... I think that none of these have been permanent, you know? Like, I don't think that any of any of the people that I've felt like I have, at one point, needed to distance myself from are people that I'm just never going to talk to again. You know, like I, I just have had to sort of put up various shields to protect myself I think

**Bushra Nayeem 14:30**

That's a good thing that you have done that. So Hannah, I would like to know about your opinion about some other institutions like health care, or government or media. I mean, what do you think, what has changed during this time? And, I mean, what is your opinion about what role these institutions play during this pandemic?

**Hannah Soyer 14:56**

Um, yeah, well, so I mean, I think that, from looking at how different countries have handled this, and from looking at the facts that we know about how our government handled it, I think that our country really failed its people in this pandemic. And, you know, I think that that, definitely, that is partially the government's fault. I mean, largely, it is the government's fault. But I also think that, unfortunately, there's this sort of American what would be the word, a mindset, okay, I think there's this American mindset of really, like, championing championing, I can't pronounce that championing there we go, the individual you know. And it's all about the individual doing this, and the individual can do whatever he or she or they want, if they put their minds to it. And I think that's the sort of culture and society that this country has. And I think that that also has greatly failed the people in this because, you know, instead of, instead of people seeing this as a communal and group problem, where, you know, okay, we're gonna take care of each other by making sacrifices, and by you know, following the safety precautions, people have people, I think, have not done that. And I think it has to do a lot with that idea of, you know, the individual versus the group. But no, I mean, I definitely think that I think that the government has a responsibility to, you know, take care of the people. And I think that there are so many ways that this specific administration has failed in that.

**Bushra Nayeem 17:34**

True, thank you, Hannah. It was really great to know your experiences and your opinions, and we're almost at the end of our conversation. And before we leave, I just want to know, from you, what was the hardest thing about living during this pandemic.

**Hannah Soyer 17:53**

Um, the hardest thing for me I think, has been grappling with the utter disregard, specifically, of disabled life, you know, the lives of people with illnesses with pre-existing conditions. That has been really hard and, and what has gone through that, in part has been seeing people that I care about, you know, because it's one thing if say, I don't know, someone in my town, who I don't really know, or maybe I don't really care too much for goes out to the bar, you know, and does all these really risky things. But it's another thing to see people I love and care about, go out and do these things that we know are simply perpetuating the problem, which then specifically affects myself and not just myself. But you know, my friends that also have really high risk conditions. So yeah, that's been the hardest thing for sure.

**Bushra Nayeem 19:01**

So have there been any silver linings?

**Hannah Soyer 19:05**

Yeah, so I think I touched on this earlier. But one of the biggest Silver Linings for me has been friends and connections that I've made within the disability community. I think, you know, there's a lot of scholarship in writing about how sort of like, group traumas bring people together. And I think in many ways, I've seen that within the disability community, because we're all experiencing this to some extent. And so I think that has been really incredible. And then also, you know, I mean, I have enjoyed spending time with my parents. I've enjoyed being home. Even though I am sacrificing various things by not being in my own space. There definitely, that for me has been great.

**Bushra Nayeem 20:04**

Yeah, it's true. I mean, I mean, this pandemic, to some extent has brought us to more closer to our relatives and our parents and our family.

**Hannah Soyer 20:15**

Oh, absolutely. It's true it's sort of, you know, it sort of forces us. And I remember I remember actually an individual by interview saying this, and I was like, Oh, my gosh, that's so true. He said, It's really forced him to really look closer at all of his relationships. And he's like, you know, because you either get closer to someone, or you have to distance yourself. And I think in some ways that can be very good.

20:45

Yeah. True. I agree with you. So thank you, Hannah. It was a pleasure to talk to you. Thank you for Thank you. Thanks. Thank you for taking your time to have a conversation for COVID Disability Archive